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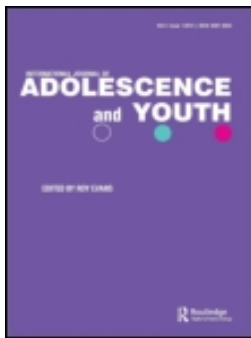
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Educational Difficulties and Support Needs of Children Following Renal Transplantation: Student, Parent and Teacher Perspectives

**Konstantina Poursanidou¹, Philip Garner¹,
Roger Stephenson² and Alan Watson³**

¹*Department of Education, Nottingham Trent University, UK*

²*Nottingham City Hospital School, UK*

³*Children and Young People's Kidney Unit, Nottingham City Hospital*

ABSTRACT

This article reports on a study that sought to map difficulties and problems in the school lives of children who have renal transplants, to investigate and evaluate the educational provision made for them, as well as to explore their support needs in relation to school. The study used a combined qualitative and quantitative research design. Individual semi-structured interviews were used with 12 transplanted children, their parents and their teachers. Statistical information on school attendance and school achievement was also collected for a number of transplanted children and their classmates/school peers. The article draws on interview material in order to illustrate and discuss key issues and areas of concern identified by the study participants. The results of the school statistics analysis are also presented and implications for practice are considered.

INTRODUCTION AND CONTEXT

The education of children with chronic medical conditions represents an area that has received limited research attention (Bolton, Closs and Norris, 2000; Lightfoot, Wright and Sloper, 1999; Bailey and Barton, 1999), notwithstanding that such conditions affect a considerable proportion of school children, amounting to 10–15% (Eiser, 1993). The focus of existing research has mainly been on issues of psychosocial and behavioural adjustment, as well as on family functioning among children with chronic illnesses (Eiser, 1993; Spirito, DeLawyer and Stark, 1991). Hence, there are

relatively few studies (completed in the United Kingdom and the U.S.A) that have focussed directly on educational dimensions of chronic health conditions (including renal failure) in children. The studies in question have documented crucial barriers to the education of children with chronic health conditions, and charted gaps in the educational provision available for them (Lightfoot, Wright and Sloper, 1998; Bolton, 1997; Norris and Closs, 1999; Closs, 2000; Larcombe, Walker, Charlton et al., 1990; Lynch, Lewis and Murphy, 1992; Fowler, Johnson and Atkinson, 1985).

More specifically, these studies have identified four broad areas of concern in the school lives of children with chronic medical conditions. The first area of concern involves academic problems mainly connected with

- frequent and long absences from school resulting in considerable gaps in learning (discontinuity of education);
- difficulties with catching up on missed work on return to school following periods of absence; and
- resulting underachievement.

The second major area of concern relates to wider aspects of social integration and inclusion, exemplified by

- exclusion from a school's extracurricular activities;
- peer relationship difficulties, including bullying; and
- problems in relationships with school staff, associated with an apparent lack of awareness and understanding of the psycho-educational implications of chronic illness in children.

Emotional/psychological issues represent a third set of important factors that may place the education of children with chronic medical conditions at risk. Such issues include low motivation for school work, as well as worries and anxieties that typically relate to academic and social difficulties surrounding re-integration into school following absence. Finally, a fourth aspect of school life that may be problematic for children with chronic illnesses, is the management of their medical needs in school on a day-to-day basis.

As regards gaps in educational provision for children with chronic illnesses, existing literature has consistently documented, among others, issues of communication and liaison between families, educators (hospital/home tutors and mainstream school teachers) and health professionals, as well as issues of co-ordination of educational support. Furthermore, the literature

in question has consistently highlighted the critical importance of teachers' awareness and understanding of their pupils' special health needs and of the impact of chronic illness on the pupils' emotional, social and educational functioning (Mukherjee, Lightfoot and Sloper, 2000; Mason, O'Sullivan and Cullen, 2000; McFarlane, 2000; Hassard, 2000).

In the opening paragraph of this article, it was pointed out that there is a relative dearth of educational research on chronic medical conditions in children at large. In the case of children with chronic renal failure (including post-transplant children) specifically, the dearth in question has been particularly pronounced. Research with these children and their families has focussed primarily on psychosocial functioning and adjustment (Shaben, 1993; Postlethwaite, Garralda, Eminson et al., 1996; Soliday, Kool and Lande, 2000; Fielding and Brownbridge, 1999; Brownbridge and Fielding, 1991; Reynolds, Garralda, Postlethwaite et al., 1991; Douglas, Hulson and Trompeter, 1998; Brownbridge and Fielding, 1989). As a result, there are relatively few existing studies addressing aspects of school functioning in this group of children (Oomen, Hulstijn-Dirkmaat, Braun et al., 2000; Lawry, Brouhard and Cunningham, 1994; Garralda, Jameson, Reynolds et al., 1988; Fukunishi and Honda, 1995; Fukunishi and Kudo, 1995; Hobbs and Sexson, 1993; Beadles, Stephenson and Watson, 1997). Moreover, the studies in question have drawn almost exclusively on quantitative data, whereas qualitative methodologies have been scarcely used. On the whole, the findings of these studies suggest problems in various areas of school functioning for children with chronic renal failure, including school attendance, cognitive functioning and academic attainment, behavioural adjustment, as well as relationships with school peers.

In summary, existing literature points to the need for further research on the education of children with chronic renal failure and chronic medical conditions at large, in view of the paucity of such research. Moreover, given that studies concerning the education of children with chronic renal failure have used almost exclusively quantitative data, there seems to be a need for a more central role for qualitative approaches in researching the educational experiences of these children. Such approaches are able to explore first-hand—and in their full complexity—the educational experiences of children by using the 'voices' of the children themselves and the perspectives of those who are most involved in their education, i.e. their parents and teachers (*cf.* Bolton, Closs and Norris, 2000). Last, the use of qualitative approaches is also consistent with many of the official policy directives and guidance

documents, which emphasise the critical importance of taking children's and parents' views of schooling into account (UN, 1989; DfE, 1994; DfES, 2001 a). The present study sought to partially fill these gaps in the research literature.

METHODOLOGY

Aims of the research

The main aims of the present study were to:

- (i) identify difficulties and problems in the school lives of children following renal transplantation;
- (ii) investigate and evaluate the educational provision currently made for them; and
- (iii) explore their support needs in relation to school, with a view to promote their effective educational and social inclusion (Closs, 2000; CSIE, 2000).

Participants

The sample consisted of 18 post-transplant children attending the Children and Young People's Kidney Unit in Nottingham City Hospital as outpatients. 10 of these children were male. At the time the present study was carried out, the children's mean age was 13.68 yrs (range 9.66–17.30 yrs). They had been transplanted at a mean age of 9.25 yrs (range 2.63–13.80 yrs). All children were at least 2 years post-transplant and at the time the research design (including sampling issues) was decided upon, they were deemed medically stable. More specifically, time post transplantation ranged from 2.05 yrs to 9.08 yrs, with mean time post-transplantation being 4.43 yrs. 3 of the 18 children had had two renal transplants. Prior to transplantation, 2 children had been on haemodialysis (involving dialysis in hospital 3 times a week) and 10 children on CCPD (Continuous Cycling Peritoneal Dialysis, involving overnight dialysis at home). The remaining 6 children had pre-emptive renal transplants, which entailed that they did not have to be on dialysis prior to transplantation.

For all children in the sample, medical staff had agreed to full-time education in a school setting. 13 of the children were at secondary school. All children were attending mainstream schools and one child (with learning and physical disabilities) had a Statement of Special Educational Needs. Children with multiple or

severe disabilities who were attending special schools, were not included in the sample, as such children form a very special population with distinct educational and psychosocial characteristics. Including such children in the sample would introduce one more variable into the present study (where the sample was already very heterogeneous), which, in turn, would raise further methodological issues of validity.

Last, it is essential to call attention to the increased heterogeneity of our sample in terms of age, gender, time post transplantation, family SES, level of parents' education, type of school attended (state/private), as well as local policy areas where the children and their families operated, given that they came from different LEAs and Health Authorities. Sample heterogeneity needs to be borne in mind in the process of interpreting the findings of the present study.

Research strategies/Methods of data collection

The present study encompassed elements of *action research* methodology, considering that i) it involved collaboration between health and education professionals from Nottingham City Hospital and The Nottingham Trent University, and ii) it was orientated towards informing changes in current educational practice through the identification of 'user' perspectives. Hence, the study had an action basis, as it sought, among others, to raise awareness and provide professional development information to educational professionals who encounter children with chronic renal failure in non-medical settings.

The study also used a combination of *qualitative* and *quantitative* methods of data collection. *Qualitative* methods involved individual semi-structured interviews with a number of post-transplant children from the sample, their parents and their teachers. Such a "multi-perspective" qualitative approach (i.e. drawing on multiple informants) enabled triangulation of our data. Interviews were conducted with 12 post-transplant children (6 male; 8 at secondary school), 14 parents and 11 teachers. The interviews, which took place in the homes and schools of the post-transplant children, took between 45 and 60 minutes and were tape-recorded.

Individual interviews with post-transplant children covered topics and areas, such as:

- (i) feelings about school (positive and less positive/negative aspects of the school experience);
- (ii) the impact of the health condition (i.e. having a renal transplant) on school life (difficulties/problems and worries concerning school work and school social life);
- (iii) relationships with teachers and school peers;
- (iv) support in relation to school problems and satisfaction with such support; and
- (v) support needs in relation to school (how support might be improved).

Individual interviews with parents and teachers of post-transplant children explored the following topics and areas:

- (i) difficulties/problems in the school lives of children following renal transplantation;
- (ii) educational provision available for these children and satisfaction with such provision;
- (iii) the support needs of post-transplant children (what would help improve their school lives);
- (iv) parents' and teachers' difficulties in supporting the learning of the children in question; and
- (v) parents' and teachers' support needs relating to the education of post transplant children.

Quantitative methods of data collection in the present study involved collecting statistical information on school attendance and school achievement for a number of post-transplant children from the sample and their classmates/school peers. The objective was to draw comparisons between the post-transplant children and their same-sex class/year averages as regards school attendance and performance. School statistics on attendance were obtained for 13 post-transplant children (7 male; 9 at secondary school) and their classmates/school peers, whereas school statistics on achievement were collated for 11 post-transplant children (7 male; 4 at secondary school) and their classmates/school peers. School attendance data covered the school years 1998/99 and 1999/2000, and consisted in percentages of attendance. School achievement data covered the school years 1998/99, 1999/2000 and 2000/01, and consisted in SATs results for English, Maths and Science from Years 6 and 9 (both actual results and teacher predictions).

Ethical issues

Ethical considerations were central to the present study, in the sense that crucial ethical issues and dilemmas arose and had to be dealt with in advance of the fieldwork, as well as during and after the data collection (Jones and Tannock, 2000; Darlington and Scott, 2002; Hollway and Jefferson, 2000). Here, we focus on three key issues, namely (i) access to the study participants, (ii) excluding children from the sample on medical and psychosocial grounds, and (iii) suspending interviews with children and parents due to medical crises.

(i) In order to gain access to the study participants (post-transplant children, parents and teachers/schools), ethical approval of the study from the Nottingham City Hospital Research Ethics Committee had to be obtained. Application for Research Ethics Committee approval involved primarily preparation of information sheets and consent forms for the post-transplant children, their parents and their teachers/schools. Information sheets and consent forms, which addressed mainly issues of "free informed consent", confidentiality and anonymity, had to be in accordance with particularly formalised and strict ethical protocols and guidelines set by the Nottingham City Hospital Research Ethics Committee. Hence, interviews with the post-transplant children, their parents and their teachers were conducted upon obtaining informed consent from the respective children, parents and teachers/schools. Interviewees were also provided with the appropriate guarantees of confidentiality and anonymity as regards the handling of the interview material. Similarly, school statistics were collected upon obtaining informed consent from the respective post-transplant children, parents and schools. Parents, children and schools were also given the appropriate guarantees of confidentiality and anonymity as regards the handling of the data on school attendance and achievement.

Furthermore, it is essential to note here that direct negotiation of access with the study participants themselves (especially the post-transplant children and their parents) proved a particularly challenging and often lengthy process. This was largely due to the fact that the extent to which participation in the study was agreeable, varied considerably with individual children and parents. For example, in some cases, children were reluctant to be interviewed themselves, whereas they were comfortable with their parents and teachers being involved in the study. Our conversations with these children's parents suggested that the

children in question might have been reluctant to re-visit painful school-related experiences and memories at interview. On the other hand, in one case, a young person was comfortable with himself and his mother being interviewed, but he did not wish his school/teachers to be contacted. In a letter addressed to myself, the young person's mother indicated that her son felt that as he changed schools soon after his transplant operation, it was "irrelevant to ask the teachers in his new school about the transplant". Last, some parents expressed concerns about putting additional pressure on their offspring's teachers, if the latter were contacted and invited to interview. We felt that the extent of involvement in the study acceptable to the participants had to be negotiated in each individual case with a great deal of sensitivity, consideration and care, in an attempt to ensure that participants retained some sense of ownership of and control over material concerning private and sensitive issues in their lives.

(ii) The target sample, which the final sample of 18 post-transplant children was drawn from, initially consisted of 33 post-transplant children/young people of primary and secondary school age. At the time the research design (including sampling issues) was decided upon, all children in the target sample were at least 2 years post-transplant and deemed medically stable. However, by the time Ethics Committee approval had been obtained and direct negotiation of access with the study participants themselves was due to begin, 1 child of secondary school age had to be excluded from the target sample on medical and psychosocial grounds. The child in question experienced a serious and ongoing kidney rejection episode that eventually led to the loss of graft and, in turn, to the child having to start haemodialysis. For this child, the medical crisis was apparently compounded by increased emotional distress brought about by extremely challenging psychosocial difficulties in his life, including death of a parent and a close friend, rejection by a step-parent, and substantial school-related problems. Upon consultation with a paediatric nephrologist in Nottingham City Hospital, we felt that it would be ethically inappropriate to invite the child in question to interview while he was experiencing medical and psychosocial stress of such kind, and, therefore, he was excluded from the target sample. Similarly, during the data collection, another child of secondary school age was excluded from the sample, since she had a kidney rejection episode, which eventually led to the loss of graft.

(iii) In the course of the interview data collection, 4 of the 12 post-transplant children interviewed experienced medical crises/kidney rejection episodes. Upon consultation with the same paediatric nephrologist in Nottingham City Hospital, we decided to suspend interviews with these children and their parents until the medical difficulties (and the psychosocial stress they gave rise to) were surmounted or receded, which we felt did justice to research ethics.

Data Analysis

Interview transcripts were content-analysed and examined for key emerging themes in progressive focus (Maykut and Morehouse, 1994). School statistics were analysed with the aid of the SPSS statistical package. More specifically, a paired *t*-test (comparing the means of matched samples) was used to compare the school attendance of 13 post-transplant children (average attendance for the school years 1998/99 and 1999/2000) to the attendance of their classmates/school peers. In a number of cases, attendance data for the school years 1998/99 and 1999/2000 could be obtained only for the target post-transplant children and not for their peers from the same class or year. In those cases, regional averages of attendance for primary and secondary school pupils had to be used alternatively (instead of class/year averages) for the purpose of comparison with the attendance figures obtained for the target post-transplant children. Similarly, a paired *t*-test was used to compare the school achievement of 11 post-transplant children to the achievement of their classmates/school peers. More specifically, the average SATs scores for English, Maths and Science from Years 6 and 9 that were obtained for the target post-transplant children, were compared with the respective class/year average SATs scores. Same-sex class/year averages of school attendance and achievement were used wherever possible. However, in some cases, same-sex class/year averages could not be estimated, so averages pertaining to both genders were used instead.

Last, it is essential to call attention to the fact that analysis of school statistics in the present study posed problems as a result of the gaps, inconsistencies and heterogeneity in the respective data alluded to above. The gaps, inconsistencies and heterogeneity in question need to be borne in mind and, subsequently, caution to be exercised in the process of interpreting the results of the school statistics analysis.

RESULTS

This section consists of two parts and presents findings from the interview data analysis and the analysis of school statistics in the present study. The first part begins with an overview of the key themes/issues that emerged in the interview data analysis. Next, interview material is drawn upon in order to illustrate and explore further the key themes/issues in question. In the second part of the section, the results of the school statistics analysis are presented and discussed.

Qualitative findings: Key emerging themes in interview data

Table 1 presents an overview of the key themes/issues that emerged in the interview data analysis. It is essential to emphasise here that this overview involves to a great extent quantification of qualitative expressions of concern that were provided by post-transplant children, parents and teachers in the present study.

One needs to recognise that such quantification of qualitative material is far from being unproblematic and, therefore, the overview in question may be treated merely as an indicative template. Table 1 presents results for 30 interviewees, namely for 10 cases where interview data are available from all three parties, i.e. the post-transplant child, the parent/s and the teacher (10 x 3). It is essential to emphasise here that although 12 post-transplant children were interviewed, this overview presents interview data only from 10 children. In the remaining two cases, interview data are available only from the children themselves and their parents but not from their teachers. Therefore, interview data for these two cases are not included in the overview, as the cases in question do not constitute "complete" cases, namely cases where interview data are available from all three parties (the post-transplant child, the parent/s and the teacher). The rationale behind including only "complete" cases in the overview, was to give some idea about the extent to which the different parties within single cases expressed similar or different concerns. Hence, it is worth noting in Table 1 below that children-as one would expect-expressed different concerns from those articulated by adults (parents and teachers). Children's concerns focussed primarily on peer relationship difficulties and issues of school absence/re-integration into school, whereas parents' and teachers' concerns involved additionally issues of educational provision/support.

As Table 1 shows, the following six key themes/issues emerged in the interview data analysis: i) peer relationship difficulties at school (endorsed by 10 of the 30 interviewees); ii) concerns related to school absence and re-integration into school following absence (endorsed by 13 interviewees); iii) lowered motivation for school work and lowered school performance linked to the post-transplant children's health condition (endorsed by 11 interviewees); iv) lack of teachers' awareness and knowledge concerning transplanted children's special health needs (endorsed by 7 interviewees); v) parents' difficulties with balancing adequate support and over-involvement in their children's education (endorsed by 9 interviewees); and vi) the importance of hospital-mainstream school liaison (endorsed by 20 interviewees). Evidently, hospital-mainstream school liaison emerged as the most important theme/issue for participants in the present study. The critical importance of effective hospital-mainstream school liaison has also been placed particular emphasis upon in the most recent official guidance document on the education of children with medical needs published by the Department for Education and Skills (DfES, 2001b). In the analysis that follows, the key emerging themes/issues referred to above are illustrated and explored further.

Peer relationship difficulties at school

Post-transplant children are likely to experience peer relationship difficulties and problems at school that tend to consist primarily in discriminatory/exclusive school peer practices, such as name-calling and other forms of bullying by school peers. Name-calling/bullying by school peers leads to the post-transplant children being at risk of social exclusion from their friendship and interest groups in the school environment, which seems to constitute a major source of emotional distress for these children. The following interview accounts, given by a primary school girl, are particularly illustrative of the effects of name-calling for post-transplant children:

"Once, a girl called Lynn called me names! When I was a baby, I had cancer of the kidney ... and they had to take both my kidneys out with my reproductive organs! And she called me something to do with that... which really upset me!"

"Last year, I also had a problem with a boy called Adrian... He said that I'd killed somebody cause I took their kidney! I think if anybody calls you that, you do feel upset, don't you? Especially when it's

TABLE 1
An overview of key emerging themes in interview data

CASES	THEME 1	THEME 2	THEME 3	THEME 4	THEME 5	THEME 6
C1	A B C	A B C	B C		B C	A B C
C2		C			B	C
C3		A B	A	A B	B	A B C
C4	A					B C
C5	A B C	A B C	C		B	B C
C6			B	B		B C
C7		B C	C	B	B	B C
C8		A B	B C	A B	C	B C
C9						B C
C10	A B C		B C	B	B C	B C
N = 30	10/30	13/30	11/30	7/30	9/30	20/30

C1–C10: Cases where Child, Parent and Teacher interviews are available (10 × 3); A = Child endorsing the respective theme; B = Parent endorsing the respective theme; C = Teacher endorsing the respective theme; THEME 1 = Peer relationship difficulties; THEME 2 = Issues of school absence/re-integration; THEME 3 = Lowered motivation for school work/lowered school performance; THEME 4 = Lack of teachers' awareness/knowledge; THEME 5 = Parents' difficulties with balancing adequate support and over-involvement; THEME 6 = The importance of hospital-mainstream school liaison

something to do with you and if you've had problems like ... had a transplant and then people go saying things like that ... So I felt really upset!"

Transplanted children in the present study also reported other incidents of discrimination/exclusion by school peers, which illustrate the close links existing between peer relationships and issues of physical appearance/body image and self-image/identity for children who are moving into adolescence. This is what an 11-year-old girl acknowledged:

"In swimming lessons, I am used to wearing a swimming costume ... not a bikini ... cause if everybody is looking at my scars from my transplant operations and past operations, I feel uncomfortable! I've had a few people say "Look at Liz Edwards!" Last year, we used to go to the town baths for swimming lessons and we used to get changed in a big changing area ... which everybody had to get changed in! And I'd got this girl and I'd take my top off and she'd stare at my tummy! She'd be staring at me and I'd be like "Have you got a problem? Because if you've got problem, will you just tell me! Because I am sick of you staring at me!" And she did that again and again and again! And sometimes, you know, I feel that I am different and some other times I feel that I'm not different! Like when I'm playing football and people let me join in! I think "I'm not treated any different, so I'm not different!"

This interview account suggests that discriminatory/exclusive school peer practices have a profoundly adverse, almost disabling, effect on post-transplant children's body image and self-image as a whole. It seems that incidents where school peers "scrutinise" and comment on the children's scars, make the latter feel "uncomfortable", even possibly shameful, about their body. Such incidents also appear to be linked to feelings of being "different" from peers, thereby reinforcing post-transplant children's sense of "otherness". Hence, school peers' attitudes towards and treatment of post-transplant children seem to play a crucial part in defining the latter's core sense of identity, which points to the critical importance of interactions with school peers as self-forming experiences for children who have renal transplants.

School absence and re-integration into school

As data on school attendance presented later in this article (see pp. 19–21) indicates, transplanted children in the present study, on the whole, seem to have a satisfactory school attendance rate. In a similar vein, interview data in the study suggests that school absence on medical grounds may be far less disruptive of

children's education post-transplant, when compared with school absence prior to transplantation and while the children are on dialysis. The mother of a secondary school male, characteristically, said:

"Since my son had his transplant, he has missed very little school... he's never ill enough to stay off! He's generally healthier post-transplant than he was before ... so, he's probably had less time off school with the transplant than before it!"

Nevertheless, issues of school absence on medical grounds and the associated difficulties surrounding re-integration into school following absence, are still likely to represent crucial areas of concern in the school lives of children who have renal transplants. School absence on medical grounds appears to have important academic as well as social parameters, entailing i) gaps in learning that may result in underachievement, and ii) disruptions in the transplanted children's participation in their school's social life. Therefore, re-integration into school following absence may involve academic and social difficulties.

The following interview accounts, given by a secondary school male, Alex, highlight academic consequences of school absence, as well as difficulties with catching up on missed school work on return to school following absence. It needs to be noted here that Alex had experienced a kidney rejection episode, which at the time of the interview was receding. He remarked that

"I am in a rejection episode that started 3 months ago! I have had to be dragged in and out of hospital nearly every week for clinic appointments! I miss a lot of school! I probably miss more than everybody put together in my class! I don't think I'm gonna get that good grades cause of all the school I've missed! Cause I miss so much school, some of the work that everybody else thinks is so easy, I find hard! "

"I don't get any help from my school to catch up with lessons I have missed! The school does not send work home! I have to catch up by myself with nobody else to help me! When I go in, I just say "Oh, sorry I'm late, Miss, I've just been to hospital!" And say that I've missed last lesson, they will just tell me to get on with the work that I missed last lesson! They wouldn't explain it very well, I'll just have to read the worksheet, which takes time cause I can't really read very fast! I'm not really very good at reading or spelling ...so, I would have to get on with that as fast as I could and then finish the work that they are doing today, which means I will have to work harder ...ten times harder than everybody else! Cause the hard that I am given is hard! Cause I miss so much school! What I have missed, is building up!"

Last, a teacher, referring to a transplanted girl in his school, placed particular emphasis on the social parameters/consequences of school absence and commented:

"There was a time last year when she was getting tired ... and a number of afternoons, after lunch, when she was really down and tired, had to go home! And not only did she miss the work, which is something she could easily catch upon in her own time ... you miss other things ... you miss social events ... you miss your friends... you're not in with what's happening around the playground as well as in the classroom! And I think this had an impact on her for a time! Not perhaps so much academically but socially ... I think she was missing what was happening with her friends!"

Lowered motivation for school work and lowered school performance

Another area of concern in the school lives of post-transplant children seems to relate to lowered motivation for school work and lowered school performance that may be precipitated by tiredness, as well as by worry and emotional distress associated with their health condition and its implications. An interview account given by a primary school teacher is particularly helpful in throwing light on this area of concern. With regard to a transplanted girl in his school, the teacher remarked:

"She can get into sort of a solemn mood... she'll say something isn't working properly or something's happened in her condition... and it obviously upsets her because she'd think that she can't do what the other children do! Her health condition does affect her because she's down... she's tired... and it all'd affect her performance! A child has got to be happy to achieve their greatest potential and some days, even though she tries to fight the condition, she is not happy because something's gone wrong! And I think if she's not happy, she's got her mind somewhere else ...on her condition! She's determined but I think the tiredness sometimes comes in... and sometimes you feel there's a bit of a low self-esteem when things aren't going right and that would impair progress to any child! When things aren't going as well as they should be, she gets low!"

Another interview account, given by a secondary school male, is also particularly illustrative of the increased worry and the profound feelings of uncertainty and helplessness that complications in transplanted children's health condition (for example, kidney rejection episodes that could lead to the loss of graft) may give rise to. One is inclined to think that in the case of the young person whose account follows, motivation for school work is likely to be affected considerably by his emotional state. He said:

"I am in a rejection episode that started in March ... we found out when I had a biopsy ... and I went in for another biopsy and my blood levels dropped ... and since then, every other clinic was that my blood levels have either gone up or gone down ... so, it's a bit weird having to be dragged in and out of hospital nearly every week! I hadn't had to go for 3 weeks since my last appointment ... but my blood levels dropped ... but I don't know whether they'll shoot up through the roof or just come back down and that! And I don't really like fighting something that I can't control and I haven't got any power over! So ... it's nothing really I can do! Just be a guinea pig really! I feel like a guinea pig! If I lose this transplant due to the rejection episode that I am having, and I'll have to have catheters in, I won't be able to do PE, I won't be able to play games ... I won't be able to do much, I won't have any energy ... I probably won't be allowed to go out at night ... I'll just have to be stuck in all night! Yes, I am worried about that!"

Lack of teachers' awareness and knowledge concerning transplanted children's special health needs

Interview data in the present study points to certain gaps in the educational provision available for children who have renal transplants. Gaps seem to involve, among others, lack of awareness and of informed, updated knowledge about transplanted children's special health needs among mainstream school teachers. Such lack of awareness and knowledge is often related to an apparent absence of effective systems of communicating and updating knowledge and information regarding the children's health condition among teachers within mainstream schools. The vignette that follows, based on our conversation with the mother of a secondary school male, Tim, is particularly illustrative of such issues of provision:

"Tim's mother identified issues of communication of knowledge and information regarding Tim's medical problems within his secondary school; in particular, the issue of passing on of such information to new staff. Tim moved schools one year after his transplant operation. In his new secondary school, teachers do not know him as they did in his old school, so they do not know his history. When he transferred to his new school, there was a meeting between parents and health and education staff about Tim's problems, but his mother did not know whether knowledge and information was passed down to all school staff. There are staff changes, so some teachers do not know about Tim's medical problems. Teachers say to Tim's mother "He looks really ill!" and she is thinking "He *is* ill!" In Tim's mother's view, what is needed is the updating of information and knowledge about pupils' health-related issues among mainstream school teachers; such "informed knowledge" would make teachers more supportive and understanding of their pupils' special health needs."

Parents' difficulties with balancing adequate support and over-involvement in their children's education

Parents of transplanted children in the present study acknowledged their difficulties and struggle to negotiate and maintain what seems to be a fine balance between being adequately supportive or over-protective and over-involved in their children's education. It could be argued that such struggle might reflect the parents' ambivalence and dilemmas relating to how they perceive and wish to treat their children. Hence, parents apparently wish to treat their children as ordinary, "normal" children of their age, but at the same time they recognise the children's individual, special health needs and "difference" as well, which seems to put parents in a double bind. By way of illustration, this is what the mother of a primary school girl reported:

"I don't know whether or not I've compromised what *could* be achieved ... But then again I don't want it to become "Liz's got a big ally in her mum as far as school issues are concerned!" I feel like ... to try and keep it ... when Liz goes to school, Liz's at school! You have to sometimes take a back step and realise that too much involvement can cause harm sometimes! Too much involvement in school and *always* being there and *always* wanting to know what's happening, can actually cause more harm than good! And Liz's become accepted within the school structure as an individual! And the children do not look at Liz as any different because I've chose to take a back step and let the school deal with issues in school!"

In this interview extract, the mother apparently wishes to be adequately supportive of her daughter's individual needs at school and, thus, she seems to ask herself questions about possible "compromises" of support on her part. At the same time, though, the mother evidently wishes to avoid becoming over-protective and over-involved in her daughter's education at all costs, as such over-involvement might bring about discriminatory treatment of the latter by her school peers and endanger peer acceptance for her.

The critical importance of hospital-mainstream school liaison

Teachers and parents of transplanted children in the present study identified good hospital-mainstream school liaison as essential, especially at times of medical crises or transition, for example from primary to secondary school. Enhancing and updating mainstream school teachers' knowledge and information levels regarding transplanted children's special health needs (both medical and

psychosocial needs), was depicted by parents and teachers as a vital purpose and contribution of systematic and effective hospital-school liaison. By way of illustration, this is what a mother said reflecting on her daughter's educational support needs at the time of the latter's transfer from primary to secondary school:

"At secondary school, my daughter's got to be prepared for big wide world and because her health is not a guarantee, I think there could be a hell of a lot more involvement when she moves up to 'secondary school and a hell of a lot more support there! I think the teachers in secondary school should be prepared as well! They should realise that going through puberty and developing stable relationships is going to be a problem for my daughter! I think the secondary school needs to be supported 100%! More mentally than anything else! If the hospital's going to become involved, then the hospital needs to set up a format where there can be this bridge between hospital and school ... and it's got to be a stable bridge and it's got to have no weak points in it at all! When she goes to secondary school, then obviously there's got to be more of an interest in her educational needs and support! From the hospital!"

Similarly, a primary school teacher commented on the need for systematic hospital-mainstream school liaison as follows:

"I think if we could have an annual review of Liz's condition with the hospital and *we* could have put the school's side across to the hospital as well, I think that would have helped *us*! It would just remind *us* about what Liz is going through, I think! Because sometimes we almost just forget that Liz has had a kidney transplant! Because she is a normal child, you know! Communication between the hospital and the school works fairly well but I think it ought to be more systematic! It would be useful if every September we could have some sort of a review meeting! And it puts the new teacher in the picture as well! Because every year Liz will have a new teacher! So, a multi-agency meeting, basically! Having annual reviews is the system for children with special educational needs i.e. particularly learning difficulties ... Because Liz is coping the way she's coped and because she is performing at a level, which is adequate for her age, we haven't gone into initiating annual reviews, really! Liz is not on our Special Needs Register because she has no learning difficulties ... she's on our Medical Register but not on the Special Needs Register!"

It is worth noting here that in the interview extract above, Liz's teacher reflects on the reasons why the need to initiate annual review meetings on his school's part had not been urgent in Liz's case. These reasons seem to relate to Liz's perceived good coping skills and to the fact that Liz is not on her school's Special Needs Register. What Liz's teacher acknowledges here, raises crucial issues of educational provision for children who have renal

transplants. One is inclined to think that transplanted children who are perceived as coping relatively well at school when discharged from hospital and are not classified as having learning difficulties, might be at risk of falling through the existing systems of educational provision and, thus, having their needs undetected and ignored. With these children in mind, the need for systematic and effective collaboration between hospitals and home schools becomes imperative (*cf* DfES, 2001b).

Last, transplanted children in the present study also commented on the importance of communication between hospital and mainstream school staff, when it comes to enhancing mainstream school teachers' knowledge and information levels regarding the children's medical condition. By way of illustration, this is what a secondary school male acknowledged:

"People from the hospital going into school are helpful ... they can explain things about my transplant a lot better than I can! Cause I don't know as much about it as they do!"

Quantitative findings: School attendance and achievement

School attendance

A mean school attendance of 85% over the school years 1998/99 and 1999/2000 was found for the 13 post-transplant children of the sample (range 66.4–92%). Mean school attendance for the post-transplant children's classmates/school peers was 94% (range 89–96.7%). A paired *t*-test showed that on average, the post-transplant children were attending 8.8% less time than their classmates/school peers, with 95% Confidence Interval of the Difference ranging from 3.9% to 13.8%. The difference was statistically significant ($p = 0.002$). Figure 1 presents the school attendance results.

It is essential to state here that on the whole, the transplanted children of the sample seem to have a satisfactory school attendance rate (85%), albeit lower than that of their classmates/school peers. Furthermore, a high standard deviation ($SD = 7.47$) was observed in the post-transplant children's sample, indicating a high dispersion of the school attendance values. This suggests that only a few transplanted children pulled down the mean school attendance rate in their group considerably.

The lower school attendance rate among the post-transplant children of the sample, in comparison to their school peers, might

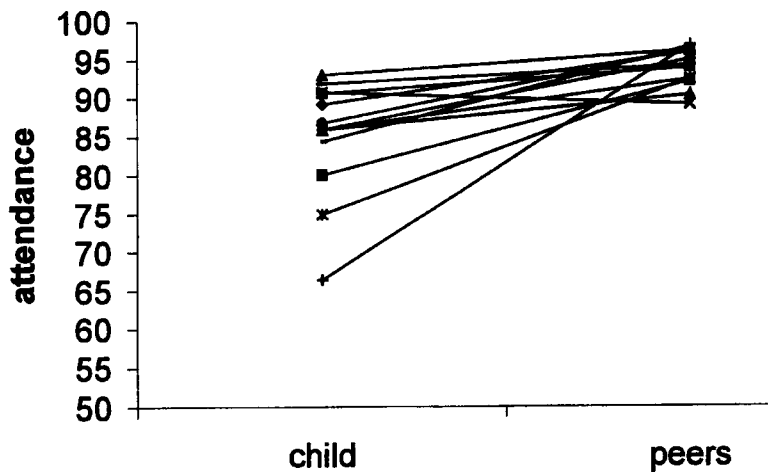


Figure 1. School attendance

be attributed to the presence of infections/ illnesses, which the transplanted children may not be able to fight as easily as their peers due to their relatively weaker immune system. It might also be attributable to family patterns of and attitudes to school attendance. The latter, for example, might apply to the post-transplant child with the lowest school attendance rate in the sample; the entire family of the child in question were described by the child's teacher as "bad attendees". On the other hand, one would be inclined to think that outpatient clinic (check-up) appointments may be rather unlikely to be responsible for the higher school absence rate among the post-transplant children of the sample, compared to their school peers, in the school years 1998/99 and 1999/2000. During the school years in question the kidney-transplanted children of the sample were, on average, 2 years post-transplant, so their outpatient clinic (check-up) appointments would have been every 3 months, on the condition that their clinical progress was deemed satisfactory. It could be argued that such relatively low frequency of outpatient clinic appointments may be rather unlikely to explain the lower school attendance rate among the post-transplant children of the sample, in comparison to their school peers.

Last, although a statistically significant difference in school attendance rates was found between the transplanted children of the sample and their school peers, much caution needs to be exercised as far as claims to generalisability of the school

attendance results are concerned. One needs to bear in mind that there are substantial limitations to generalisability, considering i) the nature of the sample (a small and non-representative sample of 13 transplanted children and their school peers), and ii) the gaps, inconsistencies and heterogeneity in the school attendance data referred to earlier in the Methodology section of this article.

School Achievement

Levels of academic performance were found to be similar among transplanted children and their classmates/school peers in the present study. A paired *t*-test showed that there was no statistically significant difference in SATs scores between the 11 post-transplant children of the sample and their classmates/school peers ($p = 0.585$). On average, the post-transplant children scored 0.12 less marks than their classmates/school peers, with 95% Confidence Interval of the Difference ranging from -0.36 to 0.61 . Figure 2 presents the school achievement results.

CONCLUSIONS AND IMPLICATIONS FOR PRACTICE

Qualitative data in the present study suggests that children who have renal transplants may experience a range of academic and

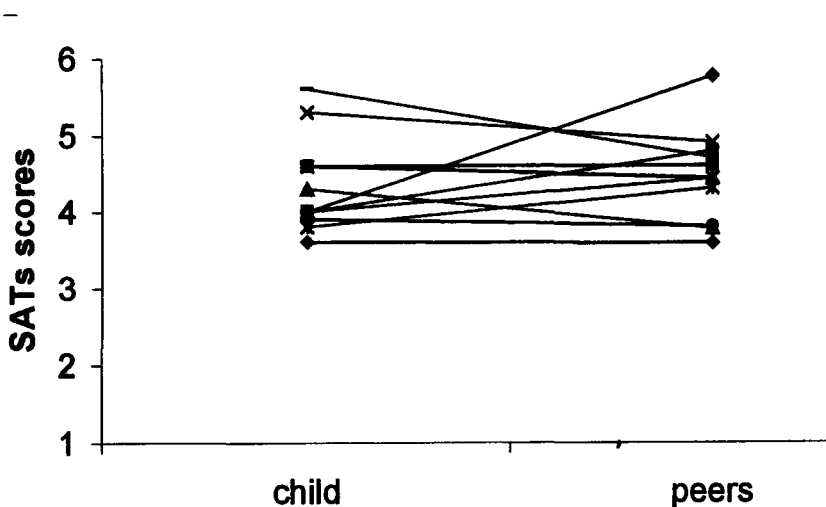


Figure 2. School achievement

social difficulties at school. Parents of transplanted children also appear to experience difficulties in their role of supporting their offspring's education. In addition, qualitative data points to gaps in the educational provision available for transplanted children, whereas good hospital-mainstream school liaison emerged as a crucial factor in providing effective educational support to this group of children. Last, the transplanted children of the sample, on the whole, were found to have a satisfactory school attendance rate, albeit lower than that of their school peers, and levels of academic performance were found to be similar in the two groups.

The findings of the present study have crucial implications for practice. The findings suggest that minimising the barriers to kidney-transplanted children's effective educational and social inclusion would require:

- Providing support to help transplanted children deal with academic and social issues; in particular, peer relationship difficulties and problems
- Raising mainstream school teacher-awareness and knowledge concerning transplanted children's special health needs (both medical and psychosocial needs)
- Improving the effectiveness of existing hospital-mainstream school liaison; this could be a crucial factor in enhancing mainstream school teacher-awareness and knowledge concerning transplanted children and their needs
- Last, addressing the support needs of parents of transplanted children in relation to their offspring's education.

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